

**Children's Special Health Services
Family Advisory Council meeting minutes
August 21, 2004**

Present from Family Advisory Council: Donene Feist (phone), Cheryl Klee, Lisa Beckman, Carla Peltier, Lori Hanson, Twyla Bohl,

Present from CSHS: Terry Bohn, Tammy Gallup-Millner, Sue Burns, Leann Bayman

Present for Medical Services: Dave Zentner

Department of Health Representative: Kim Senn

Follow-up from May meeting: Members reviewed the Review/Recommendation Form. CSHS staff will update progress on the Form before the next meeting.

Updates:

CSHS Program Reports

- The Family Handbook is nearly complete and will be distributed to families of children in the Diagnostic and Treatment Programs
- Staff will participate in an upcoming clinic coordinators meeting
- Staff have recently done site visits to PH care coordination programs and county social services offices
- There have been recent changes in Medicaid reimbursement for Metabolic foods
- The CSHS Medical Director, Dr. Wentz, will be retiring effective Sept. 20, 2004.
- CSHS has recently completed uninsured and transition mailings and has been working with the DHS public information office on having families identify the main benefits of CSHS for use as a marketing message. Members are asked to send ideas to CSHS.

Medicaid Report

- Medicaid enrollment numbers have leveled off but claims payments continue to increase.
- Medicaid will not be implementing doctor visit limits or co-pays for lab and X-Ray this year.

Title V Needs Assessment

- Members were encouraged to participate in the Title V planning retreat scheduled for October 28, 2004.
- Members reviewed summary data from the CSHS Family Survey. Many of the results are similar to the survey done five years ago. There was a 29% response rate. Financial and other impacts on families continue to be an important issue for the families of children served by CSHS.
- Results from the family focus groups and providers surveys will be completed soon and shared with Council members when ready.

Other

- Kim and Tammy reported that the Title V Block Grant review was positive
- Tammy provided an update on the Pediatric Services Task Force. Members provided the following suggestions for future addenda items:
 1. transportation (NDInfo.org transportation module)
 2. access to regular doctor (continuity of care)
 3. waiting time for appointments with specialty providers
 4. Medicaid waiver for CSHCNs
 5. Practice of medical home/care coordination by doctors
 6. Medicaid mail list of costs/payment to recipients each year.
- Terry and Tammy provided an update on the Children's Special Education Study. Child population and K-12 school enrollment is going down each year but the number of children enrolled in special education is increasing. CSHS staff will work with Special Ed., DD, and others to study this issue.
- Donene attended a medical home conference. She has materials available to share.
- It was announced the next Family Connections conference will be Sept. 30 - Oct 2, 2004 in Bismarck. Registration information is at <http://www.conted.und.edu/connections/>. CSHS has submitted an application to do a presentation.
- Kim Senn briefly discussed the following activities in the Family Health Section in the Health Department:
 1. Women and depression workgroup
 2. Early Childhood Comprehensive Systems Grant
 3. Asthma and arthritis grants

Review of Application/Eligibility /Care Coordination Forms

Sometimes county social service workers mail the forms to families applying for services, ask them to fill them out, and forward them to CSHS. Often application forms for CSHS services are filled out incompletely or inaccurately by families which can delay eligibility decisions. CSHS encourages county staff to fill out the forms together in order to establish a relationship and adequately address care coordination and service planning needs. The forms could be mailed out prior to scheduled meeting and partially filled out by the family, but ideally should be done face-to-face. Members commented that requesting services at a county social service office can be embarrassing and humbling for families.

Members were provided a list of information needed to apply for CSHS. Members made the following comments:

- Liked the idea of having a list of the information needed. It would be helpful to have time to think about care coordination needs (family strengths)
- Also include an information sheet and Family Handbook so people know about the program and what it does.
- Make sure to let families know additional information may be needed and that confidential information will be kept secure.
- Clarify terms that may be confusing such as multidisciplinary teams.

Members were also given an envelope used for the Food Stamp application that could be adapted for use by CSHS. They made the following suggestions.

- Liked the idea of an envelope so all needed documents can be kept together in one place.
- Have place to check what information is needed and what is not needed.
- Re-word first paragraph to say, “This is what you will need for the CSHS application”. Add a statement saying, “We may need additional information.”
- Get reaction from county workers
- Add a place for questions to ask the social service worker at the face to face meeting.

County Training

Members were asked to provide suggestions about agenda topics for the upcoming CSHS county training. Members shared the following ideas:

Policy

- Discuss the application process as mentioned above
- Reinforce knowing what is on the eligible condition list. Families may be able to “self-identify” conditions if the list is shown to them.
- Read and be familiar with Policy and Procedure Manual
- Know about resources and where to refer people. Have a reference guide on their desk so they can connect families to other services.
- County workers get TA from each other and CSHS office

Presentations/Speakers

1. Psychological implications of chronic illness & disability. Members discussed potential presenters. Members thought this was an important topic to cover and related experiences with their children with the following issues:

- Self-esteem
- Teasing
- Socialization
- Death
- Developmental stages
- Family stress
- Distance
- Anger
- Financial
- Family issues
- Siblings

Members suggested this topic could use a professional speaker along with a parent or youth with SHCN.

2. Medical Conditions. Discussion about having a presentation on rare conditions, or some of the more common conditions in children such as depression or ADHD, even though these are not covered by CSHS. Also suggested having presentation on genetics/syndromes.

3. Motivational Interviewing. Someone from the ND WIC program may be able to do this.
4. Another suggestion was: “The Dance of Partnership – Why Do My Feet Hurt So Much?”
5. CSHS Policy update
6. “The Magic in You!” presentation

Next meeting: Saturday November 20, 2004